

Common Data Elements for Spinal Cord Injury: Discussion Topics

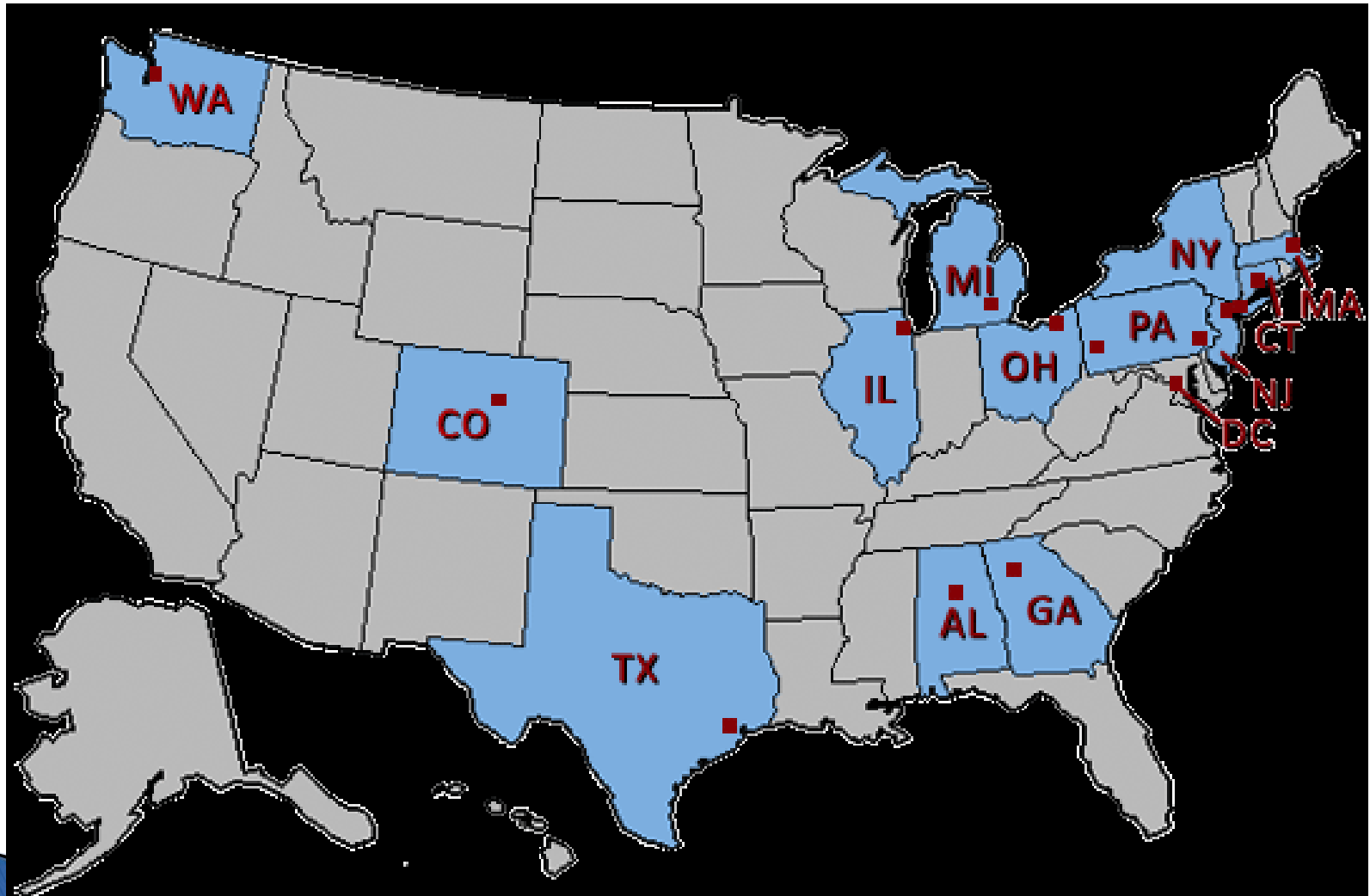
Jenny Kiratli, PhD
Director, Clinical Research
Spinal Cord Injury Center
VA Palo Alto Health Care System

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Spinal Cord Injury Care Centers

- ▶ NIDRR Model Systems of Care
 - 14 Centers currently, plus Data Center (UAB)
 - Independent facilities
 - Existing database, changing elements over time, information on >26,000 individuals with SCI
- ▶ VA SCI/D Centers
 - 24 Centers & clinics – Hub and Spokes model
 - Follow a coordinated plan of care, oversight by Office of Chief Consultant (Seattle) and PVA
 - Provides care to >26,000 veterans with SCI/D
 - SCIDO database, established in 2008, focus on new injuries/acute rehabilitation

Current NIDRR SCI Model Systems



Current VA SCI Centers (“Hubs”)

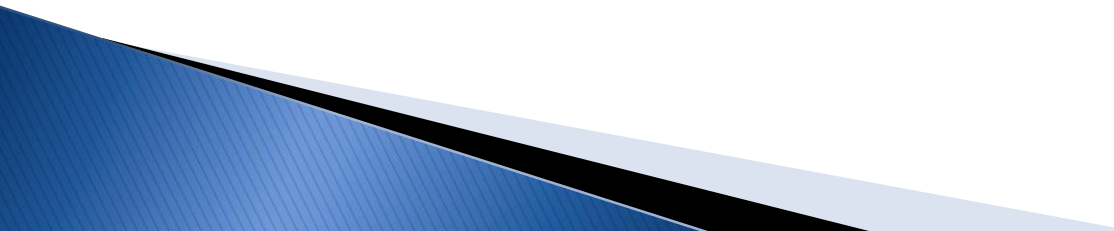


Plus 134 VA “Spoke” sites

Logistics of Data Collection

- ▶ Inclusion criteria
 - New/acute injuries
 - Chronic injuries
 - Categories of spinal cord disorder/disease
- ▶ Source of information
 - Separate data entry –or–
 - Export from medical records
 - Error–checking
 - Personnel & resources
- ▶ Data dictionary needed for consistency
- ▶ Planning for a data repository?

Questions, Queries & Considerations

- ▶ Clinical information versus research studies
 - ▶ Consolidation between centers for larger sample populations, potential for recruiting
 - ▶ Demographic studies – e.g., etiology, outcomes, medical complications, psychosocial issues, etc
 - ▶ Studies of trends – natural experiments
 - ▶ Studies of non-medical outcomes such as QOL, vocational status, caregiver information, wellness
 - ▶ Target: Consumer, providers, agencies?
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Potential Pitfalls

- ▶ Comparison across centers, between agencies
 - Different sources of medical care funding
 - Negative interpretations
- ▶ Data repository & sharing
 - What entity(ies) will oversee?
 - System to review, approve, and track data uses
- ▶ Incomplete information, lost to follow-up, etc
- ▶ Patients not followed in a NIDRR or VA Center